

HCBS Settings Rule: How to Advocate for Truly Integrated Community Settings



Created by the HCBS Advocacy Coalition

Updated March 2020

Website:
<https://hcsadvocacy.org/>

Email:
hcsadvocacy@gmail.com

Contents

Introduction & the Importance of Advocacy _____	1
HCBS Advocacy Steps You Can Take _____	5
Step 1. Evaluate Settings Early and Then Stay Involved. Don't Wait for Public Comment Period! _____	6
Step 2. Create a List of Settings where HCBS Participants Receive Services	6
Step 3. Gather and Analyze Information about the Settings on Your List _____	9
Step 4. Identify Institution-like Settings & those that Require Heightened Scrutiny _____	12
Step 5. Share your Setting Specific Information with the State _____	14
Step 6. Analyze Your State's Setting Assessment Results _____	14
Step 7. Prepare and Submit Comments on the State's STP and Heightened Scrutiny Package _____	15
Step 8. Encourage Others to Share their Opinions Too! _____	16
Step 9. Submit to CMS Your List of Settings & Critique of State Setting Assessments _____	17
Continued Advocacy _____	17
HCBS Advocacy Coalition & Contact Information _____	18

Introduction & the Importance of Advocacy

In 2014, the federal government issued the Medicaid Home and Community Based Services (HCBS) settings rule. This document refers to the HCBS settings rule as “the rule.” The rule requires that all settings that receive Medicaid HCBS funds must support individuals living, receiving day services and/or working in these settings to:

- 1) have access to the broader community;
- 2) make choices about their daily schedule in accordance with a person-centered plan;
- 3) control their personal finances;
- 4) have their dignity and privacy respected;
- 5) have a choice of a non-disability-only residential or day/workplace setting and
- 6) participate in their community in a manner that reflects their choices and individual interests.

The rule has the potential to make life-changing improvements to Medicaid home and community based services for people with disabilities and seniors. Transformation of the HCBS service system takes time to be done right. It requires planning and input from the community. For this reason, the rule gives States time to transition and a process for coming into compliance by the March 2022 deadline. This Guide will explain some of these requirements and highlight some steps in the process when it is crucial that states and the federal government hear from individuals living and working in these settings, their family members and disability advocates.

Your opinion matters!

Your state and the Centers for Medicare and Medicaid Services (CMS), the federal agency that issued the HCBS settings rule, are working now to make sure that all HCBS settings that receive Medicaid funding meet all the rule’s requirements. If they determine that a setting that does not, the state must make decisions on how to improve the setting so that it meets all the requirements by March 2022 or remove the setting from its HCBS program and

instead fund it outside of the Medicaid HCBS program. The best source of information on whether the setting you live or work in supports you to be as independent as you want to be, experience privacy and respect, appropriately control your daily schedule and participate in the community – Is You! Family and friends that know about the place where you live and work and are also encouraged to send comments to your state and CMS.

The rule means that everyone who receives HCBS services should have the same access to their communities as individuals not receiving HCBS.¹ The rule provides an important opportunity for states to improve these settings and make sure they are truly community-based. Under the rule, community-based settings should not have policies and practices often found in nursing homes and institutions that restrict community participation and choice. This is also a time for states to decide whether more they need more of certain types of HCBS settings, such as more individual rather than group settings, to meet the rule's requirements.

To learn more about the basics of the rules, check out "[The Medicaid Home and Community Based Services Rules: What You Should Know.](#)" and other resources on www.hcbsadvocacy.org.²

The HCBS Settings Rule allows states until March 2022 to evaluate all their HCBS settings and make the improvements necessary for all settings to be in compliance. Full compliance requires states to take three steps. First, states must develop an initial statewide transition plan (STP) for coming into compliance with the rules. An initial plan looks at the state's policies, procedures, licensing requirements, provider manuals and other similar guidance to ensure they don't conflict with the settings rule and that they support the rule. Initial STPs must be put out for public comment before they are submitted to CMS for approval. As of March 2020, all but six states have received approval of their initial STPs.³

The second step is the development and approval of a final STP. A state's final STP must provide information on the process used and results of the state's assessment and validation of every Medicaid funded HCBS residential and day setting. States must seek public comment on their final STPs, as well as the results of any later assessments. Approximately half of states have received final approval for their final STP as of March 2020.

The third step – which can happen at any time – is for states to identify settings that currently receive HCBS funding but that are considered “presumptively institutional” under the Rule. There are three categories of settings that are considered “presumptively institutional:

- 1) those located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment;
- 2) those in a building located on the grounds of, or immediately adjacent to, a public institution; or
- 3) any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of those not receiving Medicaid HCBS.

In March 2019, CMS released guidance describing the factors for the last category of presumptively institutional settings, settings that isolate. A setting that isolates has any one of these characteristics:

- Due to the design or model of service provision in the setting, individuals have limited, if any, opportunities for interaction in and with the broader community, including with individuals not receiving Medicaid-funded HCBS;
- The setting restricts beneficiary choice to receive services or to engage in activities outside of the setting; or
- The setting is physically located separate and apart from the broader community and does not facilitate beneficiary opportunity to access the broader community and participate in community services, consistent with a beneficiary’s person-centered service plan.

States may add additional factors beyond those set by CMS in defining a setting that isolates but must clearly identify those additional factors so that stakeholders can understand what the state considers isolating.⁴

If the state believes a “presumptively institutional” setting can overcome the institutional presumption and comply with all aspects of the rule, they must put together a package of evidence as part of the “heightened scrutiny process.” The public has the opportunity to comment on the evidence package before it

is submitted to CMS. A state need not submit a heightened scrutiny package to CMS for settings that isolate that have remediated and fully comply with the rules by July 2020. However, those settings must be listed in a STP for public comment or otherwise been available for public comment.⁵ A state may go through the heightened scrutiny process at any time or even multiple times before the March 2022 deadline for compliance with the rules.

For more information about the heightened scrutiny process, check out these additional resources:

- The Medicaid HCBS Settings Rule: Heightened Scrutiny (from the HCBS Advocacy Coalition): <https://bit.ly/33uclqT>
- Identifying, Evaluating, and Remediating “Settings That Isolate” in the Context of CMS Guidance on Heightened Scrutiny Requirements within the HCBS Settings Rule (by Community Living Policy Center): <http://materials.ndrn.org/HCBS/HCBS-Settings-Heightened-Scrutiny-CLPC-Document-Feb-2020.pdf>
- CMS Guidance on heightened scrutiny: <https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/smd19001.pdf>
- CMS Slides from webinar on heightened scrutiny <http://materials.ndrn.org/HCBS/CMS-Heightened-scrutiny-presentation-3-28-19.pdf>

Importance of Advocacy

The extent to which the HCBS settings rules are a catalyst for positive change will depend on the strength of each state’s transition plan and efforts of stakeholders to influence the plan and monitor its implementation. It is an important time to be involved in advocacy efforts. Your efforts can impact the way the rules are implemented in your state. CMS has stressed the importance of public comments and that they are looking closely at state outreach and response to public comments. Advocates’ voices matter!

Input from advocates and HCBS participants from their knowledge about the HCBS settings in a state’s system is critical. States must accurately identify the settings that need to change, such as those that isolate a person from the

community, restrict choice, or generally operate like an institution. Input from advocates about settings helps ensure states implement the rule so that HCBS participants receive the benefits of, and are fully included in, the broader community. Therefore, participation in the settings assessment process, particularly commenting on setting assessment results, is important for advocates looking to advance community integration.

Advocacy is necessary to ensure faithful implementation of the rules. HCBS participants and stakeholders have their own, crucial setting-specific information to inform their comments and enrich the process.

HCBS Advocacy Steps You Can Take

9 Advocacy Steps to Advance HCBS

The following are steps advocates should take to use the HCBS settings rules to advocate for integrated community settings:

1. Evaluate HCBS settings in your states' system as early as possible; do not wait for the public comment period!
2. Create a list of settings where HCBS participants receive services – residential, day programs and work.
3. Gather and carefully study the information about the settings on your list.
4. Identify institution-like settings and those that should require heightened scrutiny.
5. Share your setting specific information with the state.
6. Analyze your state's setting assessment results when it posts them for comment.
7. Prepare and submit your comments on the state's statewide transition plan (STP) and/or heightened scrutiny requests.
8. Encourage other advocacy groups, HCBS participants and their families, and individuals you work with to engage in public input.

9. Send the list of settings you reviewed and include your opinion about your state's setting assessments to CMS.

Step 1. Evaluate Settings Early and Then Stay Involved. Don't Wait for Public Comment Period!

The assessment of states' HCBS settings should be an ongoing process for advocates, just like it is for the states. Although a state might only have a formal public comment period after it has completed the setting assessment process, advocates should continue to actively gather information, communicate with the state, and stay involved. Ongoing involvement of advocates helps ensure the assessment process is accurate and the results reflect the actual experience of people in those settings.

Gathering information on HCBS settings will likely take some time. States have a large number and different types of settings in their system so information gathering may be time consuming. There may also be delays in gathering information from other advocates, participants or providers, or getting responses to public record requests.

Preparing well in advance allows advocates to have the information they need already gathered so they can use the comment period to compare the information they have gathered with the state's assessment. Gathering information before the comment period helps advocates create detailed and, specific comments. Preparation also helps advocates have time during the comment period to organize other advocates and HCBS participants to also comment.

Step 2. Create a List of Settings where HCBS Participants Receive Services

Create a list of HCBS settings from which you can identify settings that do not meet the HCBS requirements or are institutional in nature, including settings that isolate. Not all settings where HCBS participants receive services may be

Medicaid funded. However, if the source of funding is not clear, it is easier to include the setting on the list and allow the state to respond that the setting is not HCBS funded. Below are some possible sources of information about setting types and locations, as well as ways you can use the sources to identify problems with the settings:

- **State HCBS waiver documents, such as approved applications or amendments, and State plan documents.** The “Services” section of these documents should identify the types of providers who can provide the covered service. This list of settings can act as your starting universe of settings to consider.
- **Provider listings for individual types of HCBS.** This could include listings used by participants to look for residential or day service options. You may be able to access this information on a state website or through a public records request. As with any public records request, it helps speed up the response when you narrow the request on the information you really need, such as identifying specific provider types.
- **Provider websites.** Sometimes larger providers have listings of their different setting sites. If there is a concern about the way a particular provider operates their settings, this could be a good source of information as the provider may operate other settings in a similar way. Provider websites may also help you identify settings that are concerning due to their physical proximity to one another, which can promote institutional characteristics within the settings. For example, is one of the “selling points” of a residential setting that it is convenient to the provider’s day program or other services?
- **Provider trade organizations.** There are state and national trade organizations for many provider types. If you are concerned about providers of a certain service in your state, such as sheltered workshops, facility-based day programs or residential campuses or gated residential communities, it may be useful to look at these trade organizations to identify providers of those services from their membership lists.
- **Managed care organizations.** Managed care organizations (MCO) have provider networks, so they should have listings of types of providers. As part of the MCO provider approval process, the MCO may also have complaints or other relevant information about the provider.

- **Licensure listings.** Because such listings are by type of license, these can be particularly helpful if you identified features of certain settings based on their licensure requirements. For instance, if the licensure requirements allow activities not permitted by the HCBS regulations, such as limited visiting hours. Alternatively, the licensure requirements may be silent on certain requirements in the HCBS rule, such as participant choice and control over daily life activities, and you may know that such settings lack these required features of a community-based setting.
- **Licensure reviews, surveys or inspections.** Annual reviews or inspections of settings or findings of violations will likely provide information about the nature of the setting. This information should be available from the licensure agency or whichever agency is responsible for such surveys and inspections.
- **List of 14(c) certificate holders and Community Rehabilitation Programs.**⁶ Certificates under 14(c) allow employers the right to legally pay people with disabilities a subminimum wage – meaning a wage less than that paid to workers without disabilities.⁷ The listing of 14(c) certificate holders should help in identifying segregated day programs that operate as sheltered workshops. Such settings often limit participant interaction with people without disabilities and access to the broader community.⁸ Employers who hold these certificates in your community should be looked at closely.
- **HUD website.** Some states have 811 projects, which are often disability-specific housing. [HUD's website](#) maintains a list by state of HUD-funded housing that identifies 811-funded settings and how many of the units are targeted to people with disabilities. Some, but not all, 811 housing is targeted to a specific type of disability, and those that are may merit a closer look at residents' experiences in those settings. The placement of the housing may also trigger closer scrutiny for other nearby settings. For example, if the housing is close to a day program, congregate residential facilities, or institutions, it could indicate that it is a setting that isolates residents from the broader community.
- **County/city tax information.** The tax information available online from local governments can provide useful information about properties owned by the same corporation (from property owner search); proximity of properties to one another, particularly if properties are contiguous (through

property maps); whether property is located in a residential or industrial zone (from property maps and zoning layers); and other information.

- **Google Maps and Google Earth.** Google Maps can provide information, including a street view of a setting, from which you can gather information relevant to rule compliance, such as size, proximity to other settings where multiple people with disabilities live, and proximity to community resources (i.e., is the setting in town, walkable to transportation, close to possible employment). Google Earth provides access to good satellite imagery and additional information, and importantly, allows you to make a map on which you can plot the different types of settings. Such a map may allow you to more easily see the relationship of settings to one another and give you a better idea about geographic isolation that may contribute to the isolated nature of a setting.

Step 3. Gather and Analyze Information about the Settings on Your List

STPs are required to identify the types of settings that provide HCBS. Advocates may not be able to evaluate or gather information about every setting. However, advocates will likely know the types of settings that are most likely to have the biggest issues with complying with the HCBS settings rules. Gathering meaningful information about several different examples of problematic settings for each type of setting will help show the state how those settings function for the participants, how the settings need to change to meet the HCBS rules, or that they will not be able to meet those rules.

In gathering information, look for evidence that the settings have characteristics that isolate individuals from the community, as well as settings that are in or on the grounds of institutional settings. If you find such settings, be detailed and specific about the characteristics that support these findings. Use the CMS “Exploratory questions for settings” (both residential⁹ and non-residential¹⁰) and other CMS guidance as a guide for what to details to include.¹¹ As much as possible, this information should include evidence about:

- How an individual experiences the setting, and
- The specifics of the setting and how it does not meet the rule.

How an Individual Experiences the Setting

To the extent possible, gather information about the experiences of individuals in these settings and how these experiences compare to the requirements of the HCBS rule. This would certainly include any information directly from participants, their families, advocates with direct knowledge and similar individuals. It could also include information from former or current staff. Advocates may also find useful information in reports from monitoring efforts or even from licensure reviews. Working with other advocacy organizations, especially self-advocacy groups, is critical because bringing everyone together to mine for information about settings will be much more effective than individual groups trying to gather this type of information.

The Specifics of the Setting

This should include information about how the setting currently does or does not meet the HCBS rule. Consider asking these questions for each setting:

- Does the setting offer a range of services on-site, such as medical, financial, independent living and other services? Such “in-house or onsite” services often limit autonomy and options, “independence in life choices,” and individual choice in who provides services and supports, as required by the rule.¹²
- Does the setting have a policy that visitors must be pre-approved and have an appointment or only visit during “house hours”? This violates the requirement that “[i]ndividuals are able to have visitors of their choosing at any time.”¹³
- Does the geographic location of the setting lead to isolation from the broader community? Is the setting close to other settings that serve individuals with similar disabilities? Settings that are all owned/operated by the same provider indicate a high likelihood that there is operational interrelatedness among the settings. Such settings may create an isolated enclave or campus of people with disabilities that are very institutional in nature. Look for:
 - Shared transportation, such as a van for multiple units, which indicates a likelihood that community activities are likely very scheduled to

- accommodate the needs of the multiple units and which significantly impair choice of activity and the autonomy of the individuals.¹⁴
- Shared dining or recreation facilities which would indicate operational connectivity between settings.
 - Evidence that all the residents are employed at the same business or attend the same day program.
 - Is the primary purpose of the setting to deliver services, such as employment, to people with disabilities only?
 - Are the majority of people present in the settings (other than paid staff) people with disabilities? If there are people without disabilities in the setting, are they in different parts of the setting? For example, in an employment setting, do people with disabilities and those without disabilities work in segregated work areas in the same building?
 - Is there meaningful participation in community events and activities in ordinary community venues (not owned, operated, or leased by HCBS providers) such as fitness facilities, community centers, recreation centers, libraries, community colleges, religious centers, etc.?
 - Does this participation occur when these venues are open to the general public and include participants who are community members without disabilities and who are not paid staff of the provider?
 - Do participants have routine and frequent opportunities, of their choosing, to access services available to the general public?
 - Does the setting provide readily available support for getting to activities and opportunities?
 - Are there restrictions on when or how often an individual may use such supports?
 - Is there available staff who are properly trained who can help individuals access other services that can help them obtain and maintain competitive employment in integrated settings?
 - Are the activities individually-planned and delivered or do they occur in groups?
 - Does the type and range of available activities allow for a meaningful day that is comparable to individuals without disabilities of a similar age? This

could include educational, recreational, familiar, social, faith-based, volunteer experiences, and employment opportunities.

- Does the setting maximize an individual's opportunities for engaging in meaningful day activities outside the home?
- Does the setting facilitate contact and interactions with community members without disabilities?
 - Does this occur outside the setting?
- Do the activities maximize independence (social, interpersonal and economic), autonomy, and self-direction?
- Does each individual in a setting have their own choices and flexible schedule (not group or facility-based schedules)?¹⁵

In reviewing settings that may isolate people with disabilities, CMS will specifically be looking at:

- Does to the design or model of services result in individuals having limited or no opportunities to connect with the broader community, including with individuals not receiving Medicaid-funded HCBS;
- Does the setting restrict the person's choice to receive services or to engage in activities outside of the setting; or
- Is the setting is physically located separate and apart from the broader community? If yes, does it make it easy for people to have a chance to access the broader community and participate in community services, in a way that matches what's in each individual's person-centered service plan?
- Your state may look at additional things to decide if a setting is "isolating", and if they do, the state must clearly say what those other items are.

Step 4. Identify Institution-like Settings & those that Require Heightened Scrutiny

There is no magic formula or key feature that identifies a setting as institutional or as a setting that needs to change to become sufficiently community-based to meet the rule. Because the rule focuses on the experience of the individual, the same type of setting, e.g., a 4-bed residential facility, could be institutional or

community-based depending on where it is, the policies in place, how it is run, and the opportunities of individuals who reside in that facility.

Although there is no simple test, there are some things advocates should do when thinking about how to identify possibly problematic settings:

- Review CMS guidance on heightened scrutiny, exploratory questions for residential and non-residential settings, and settings that isolate.¹⁶ Although you may have read these pieces of guidance when they first came out, it is helpful to remind yourself of what CMS has said. It can also help you pick out pieces that you know you will want to cite to in your comments when you are highlighting ways a setting does not comply with what CMS has said is required or is an indicator of a non-community based setting.
- Brainstorm about possible settings that receive HCBS funding and that could be isolating based on location, size, or relationship to other institutional settings:
 - Settings on the campus of an ICF-ID/DD, nursing facility or other similar institutional setting. This would include looking for both residential and non-residential settings connected to such facilities.
 - Settings on former institution grounds.
 - Large, congregate settings that specifically cater to people with disabilities, including assisted living, farmsteads, gated communities, apartment communities with additional services or amenities that are targeted to older adults or people with disabilities.
 - Smaller facilities, such as group homes or more independent living situations, grouped in close proximity. For instance, multiple homes on the same street. Licensure listings can be helpful in identifying such settings-based operators and location.
 - Co-location of day and residential settings.
 - Geographically isolated, segregated day settings that seem unlikely to provide much interaction with the community.
 - Large, congregate day settings comprised primarily or exclusively with people with disabilities and limit their choice of daily activities in the setting. Examples include sheltered workshops and some day habilitation programs.

- Identify any licensure or other features that could then be used to indicate similar types of settings. As discussed above, licensure information can be helpful in identifying institutional indicators such as the size of a facility, staffing ratios, rights protections, or lack thereof. Once a type of setting has been identified as isolating or otherwise problematic, the licensure information can be used to identify similar settings and can also provide information on settings owned or operated by the same entity.

Step 5. Share your Setting Specific Information with the State

Once you have compiled your information, in collaboration with other groups, share that information with the state. Ideally, you should share some of this information while the state is still conducting its own assessments. Sharing in advance of final results can help influence the state's process and highlight potential issue areas with settings and with the process itself. If your state has already made public some of its preliminary results, be sure to highlight where your findings differ from the states' findings.

Step 6. Analyze Your State's Setting Assessment Results

Once a state has completed the results of the settings assessment, it must release the information for public comment through an amended STP. The information you have already gathered should be very helpful in evaluating the states' assessment results. Remember, as you evaluate the results, keep in mind (and handy) the CMS guidance so you can easily note if there is something stated incorrectly in the results and/or where there is a conflict between the guidance and state's statements. You can do the same with the information you have gathered on settings. In particular, look closely at the amount and specificity of the state's justifications for why each setting is not institutional or meets the characteristics of an HCBS setting. This information must be in the STP. CMS guidance lays out the type and specificity of evidence it expects, particularly if a setting is being submitted for heightened scrutiny.¹⁷

The following are some questions you may want to ask as you go through the state's assessment results:

- Do the updated plan and assessment results appropriately categorize different types of settings?
- Are all of the settings included in the results that should be? Which settings are missing?
- Look for known settings and compare those results to previously gathered information to check whether the information in the state's assessment results is accurate.
- If the state is submitting any settings for a heightened scrutiny review:
 - Does the setting overcome the presumed institutional characteristics?
 - Is sufficient information provided that describes the experiences of individuals in the setting and proves the degree of community integration required by the rules? Is additional information necessary?
 - If the setting does not meet the criteria, gather together information that challenges the state's information and provide a detailed comment.
- Identify in your comments any settings that are incorrectly categorized as compliant with the HCBS rules but should be categorized as "presumptively institutional".
- Identify in your comments settings that the state has not identified at all. This is particularly relevant for settings that should be identified as settings that isolate and therefore should be submitted for heightened scrutiny if the state wishes to continue their use. Many states do not have good processes for identifying these settings, so this is a key area for identifying problems and comment.

Step 7. Prepare and Submit Comments on the State's STP and Heightened Scrutiny Package

Commenting on setting assessment results will likely be different from the typical comments most advocates submit. The comments on settings should have a level of specificity that is not often necessary when commenting.

Advocates should draw from the evidence they have gathered about the individual setting and the individual's experience to make a case for how the characteristics of that setting do or do not match the specific requirements of the rule. Including specific evidence in the comments should help force the state to be similarly specific in processing the information on the settings and in responding to the comments with reasons why, if the state makes no changes to the plan, the state did not alter its findings.

Advocates need very specific information from the state's assessment process to be able to identify the settings in question and then provide information. Personally, identifiable information should not be available about individual participants. Also, specific information about an individual's experience that could potentially identify the individual or release inappropriate information about that individual, e.g., restrictions on their freedom due to a certain health condition that thus reveals the health condition, should be protected. However, this does not mean that the state can provide information about settings in such a way that is very general and thus does not give stakeholders sufficient information to understand how a setting has been assessed. The state must provide enough information to allow meaningful comment¹⁸ within the limit of applicable privacy law.¹⁹ In commenting, advocates should also review the updated STP and compare it to the issues CMS has raised with the state in any public correspondence, including in its letter to the state along with initial approval describing additional steps necessary for final approval.

Step 8. Encourage Others to Share their Opinions Too!

It is really important that advocates let stakeholders know about the opportunity to comment on the state transition process. When doing this type of advocacy, the number of comments submitted is important because it shows that multiple people or groups share a concern or idea. Please encourage other advocacy groups and individuals to send in their own comments rather than sign on to those of another's group. Encourage people receiving services and their family members to share their opinions! Every opinion matters! For materials explaining the basics of the rule and why involvement is important, visit <https://hcbadvocacy.org/>.

Also, advocates should provide tools to help stakeholders understand the STP, the public comment process, and any other stakeholder input process the state may be using, such as a stakeholder transition committee. When possible, develop a sample template for commenting. This sample template might prompt people to tell their story about experiences in certain types of settings or what they value in a community-based setting. As discussed above, comments are really important and can significantly affect settings across a state.

Get started early, gather relevant information, draft comments, and make it as easy as possible for others to do the same!

Step 9. Submit to CMS Your List of Settings & Critique of State Setting Assessments

While states must respond to public comment and provide their response to CMS, they only send a summary to CMS. After the state issues the transition plan with the response to comments, review how the state responded to your comments. If you think that they did not make sufficient changes and did not offer reasonable explanations as to why those changes were not made in their response to comments, you may consider sending your comments to CMS with the full list of specific settings identified. If you choose to send your comments to CMS, you should send them with a cover letter highlighting the areas that the state failed to respond to and the settings that most concern you.²⁰

Continued Advocacy

Implementation of the HCBS rule is a long-term process and will require advocacy throughout to make sure that each state is doing it right. However, this does not mean that the advocacy must always be resource intensive; much of the work is more about monitoring the state process. Advocacy is important throughout the process, but especially in the STP and assessment process to make sure that the states have strong plans to follow. Also, the national organizations listed on this document are all working on how HCBS is being followed by states and are working collaboratively to assist state advocates in understanding the process, evaluating state plans and assessment processes, and crafting effective comments and plans for

advocacy. State advocates may contact these organizations through emailing hcbsadvocacy@gmail.com and the organizations will coordinate to try to provide assistance.

HCBS Advocacy Coalition & Contact Information

HCBS Advocacy Coalition

Website address: <http://hcbsadvocacy.org/>

Email address: hcbsadvocacy@gmail.com

The HCBS Advocacy Coalition is a coalition of national organizations working together to support full inclusion of people with disabilities and older adults through implementation of the HCBS Setting Rule:

[American Civil Liberties Union](#)

[American Network of Community Options and Resources](#)

[Applied Self-Direction](#)

[Association of People Supporting Employment First](#)

[Association of University Centers on Disabilities](#)

[Autistic Self Advocacy Network](#)

[Bazelon Center for Mental Health Law](#)

[Center for Public Representation](#)

[Council on Quality and Leadership](#)

[Collaboration to Promote Self-Determination](#)

[Human Services Research Institute](#)

[Justice in Aging](#)

[National Association of Councils on Developmental Disabilities](#)

[National Consumer Voice for Quality Long Term Care](#)

National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Health Law Program
National Leadership Consortium on Developmental
Disabilities
TASH
The Arc

¹ The settings rule is for both residential and other settings such as work or day programs. These new HCBS regulations were effective in March 2014. The new regulations set up new rules for how states can use Medicaid to provide Home and Community-Based Services. The new rules were created to improve the quality of HCBS. They will also provide additional protections to HCBS participants. The rule can be downloaded at:

<https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>.

² HCBS Advocacy Coalition, HCBS Settings Rules—What You Should Know, http://materials.ndrn.org/HCBS/HCBS-Settings-Rules_What-You-Should-Know-5-13-19-final.pdf

³ Illinois, Maine, Massachusetts, Nevada, New Jersey, and Texas have not received initial approval as of March 2020. CMS, HCBS Statewide Transition Plans, <https://www.medicaid.gov/medicaid/home-community-based-services/statewide-transition-plans/index.html>.

⁴ CMS, Home and Community-Based Settings Regulation – Heightened Scrutiny SMD #19-001 (Mar. 22, 2019), <https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/smd19001.pdf>.

⁵ *Id.* at 2-3.

⁶ U.S. Dep't of Labor, <http://www.dol.gov/whd/specialemloyment/BusinessCertList.htm>; <http://www.dol.gov/whd/specialemloyment/CRPlist.htm>.

⁷ See 29 U.S.C. § 214 and Department of Labor Factsheet <http://www.dol.gov/whd/regs/compliance/whdfs39.pdf>.

⁸ For examples of how these settings can segregate individuals from the community, see, for example, Department of Justice letters finding the states of [Oregon](#) and [Rhode Island](#) in violation of the Americans with Disabilities Act because of their over-reliance on segregated sheltered workshops. See also National Disability Rights Network, Segregated and Exploited: the Failure of the Disability System to Provide Quality Work (Jan. 2011), <http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Segregated-and-Exploited.pdf>.

⁹ CMS, Exploratory Questions to Assist States in Assessment of Residential Settings, <https://www.medicaid.gov/medicaid/hcbs/downloads/exploratory-questions-re-settings-characteristics.pdf>.

¹⁰ CMS, Exploratory Questions to Assist States in Assessment of Non-Residential Home and Community-Based Service (HCBS) Settings, <https://www.medicaid.gov/medicaid/hcbs/downloads/exploratory-questions-non-residential.pdf>.

¹¹ CMS, Home & Community Based Settings Requirements Compliance Toolkit, <https://www.medicaid.gov/medicaid/hcbs/guidance/settings/index.html>.

¹² 42 C.F.R. § 441.710(a)(1)(v); § 441.710(a)(1)(vi).

¹³ 42 C.F.R. § 441.301(c)(4)(vi)(F).

¹⁴ Transportation should also meet the needs of the facility it serves. For instance, if a facility serves individuals who use wheelchairs, is the van accessible and does it have sufficient tie-downs to accommodate the individuals or do people need to stay behind due to transportation limitations.

¹⁵ Although the questions in this section do not generally come from any guidance, they are intended to help identify institutional qualities in settings and other issues related to the rules.

¹⁶ These documents can be found in the CMS Home & Community Based Settings Requirements Compliance Toolkit,

<https://www.medicaid.gov/medicaid/hcbs/guidance/settings/index.html>.

¹⁷ Heightened Scrutiny guidance, *supra* note 4.

An earlier CMS document on Heightened Scrutiny FAQs from June 2015, with some potentially useful and detailed information is available at:

<https://www.medicaid.gov/medicaid/hcbs/downloads/home-and-community-based-setting-requirements.pdf>, but note that some of the information has been replaced by later guidance.

¹⁸ If advocates are concerned about including certain information in their comments about settings or the experience of individual participants, they can consider drafting a public version of their comments that removes overly identifying information and submit a more specific version to the state, citing freedom of information act requirements when requesting that pieces of the comments not be released publicly or be redacted, unless to CMS. The same is true if advocacy with the state is ineffective on settings and advocates write to CMS and include the specific comments. Advocates can cite to HHS FOIA regulations, 45 C.F.R. §5.67(c), to request that CMS protect personally identifying information found in the comments. (citing that "...addresses of individual beneficiaries of our programs" would often be a "clearly unwarranted invasion of personal privacy.")

¹⁹ CMS specifically addressed the HIPAA question in the March 2019 guidance in Question 6. Heightened Scrutiny guidance, *supra* note 4 at 4-5.

²⁰ Note that in the [Heightened Scrutiny guidance](#), CMS said that for the heightened scrutiny process, they will specifically review settings that generate significant public comment in opposition of the state's assessment. Public comment will continue to play a very important role at all stages of implementing the rule.